ALS is a rapidly degenerative neurological condition that attacks the nerve cells that control voluntary muscles. There are generally two ALS types: bulbar initially involves the cranial nerves impacting speech and swallowing and spinal initially involves the spinal nerves impacting limb movement. Two recent reviews describe AAC intervention and decision-making for persons with ALS (Ball, Beukelman, & Bardach, 2007; Ball, Beukelman, Anderson, Robertson, & Pattee, 2007). For this presentation, the authors propose to provide new data from the Nebraska ALS database applied within a framework of personnel who support persons with ALS with CCN.

For persons with ALS, eye-tracking technology is now more accessible and dependable. This technology has provided options for persons with even the most limited head movement. Among individuals with acquired CCN due to ALS, AAC intervention is widely accepted and is likewise accepted by their families and personnel who assist them. Intervention breakdowns or failures typically occur at a personnel level, where even a single person can impact success (Beukelman, Fager, Ball, & Dietz, 2007). Data on use patterns of eye gaze technology by persons with ALS through June of 2008 will be presented from the Nebraska AAC/ALS database.

For successful AAC interventions to occur, several categories of individuals are critical. In this session, a personnel framework is presented to support various areas of communication need for persons with ALS. The authors introduce AAC finders, AAC general practice clinicians, AAC specialists, AAC facilitators, and AAC experts. Specific roles for each personnel category are described and supported with data from the Nebraska AAC/ALS database.

For persons with ALS, Ball, Beukelman, & Bardach (2007) describe three phases of AAC need/intervention. AAC finders play a particularly important role in AAC services during Phase 1 of intervention - known as the Monitor, Prepare, and Support Phase (Ball et al, 2007). Finders need to know that 95% of people who continue to live with ALS eventually lose the ability to meet their communication needs through natural speech. Of this group, nearly all (96%) accept AAC when served in a timely manner and when prepared for AAC related decisions (Ball, Beukelman, & Pattee, 2004). No differences in acceptance rate are found for males versus females. This acceptance rate is considerably higher than it was 12 years ago (Guttman & Gryfe, 1996). In a recent report (Ball, Beukelman, Roberts, & Anderson (in press), 100% of individuals with ALS, who accepted AAC technology, used it until within a relatively brief period (a few days to a month) prior to their death.

Unlike traditional clinical thinking, speech intelligibility measures tend to be relatively ineffective in predicting loss, thus impacting AAC intervention strategies. This is compounded by the fact that there is too little time between intelligibility reductions and inability to meet communication needs. If clinicians rely on intelligibility to assess speech of the individual with ALS; often the person has severe CCN before the AAC evaluation and the timing is delayed. This includes AAC recommendations, obtaining a prescription for the recommended technology, procuring the technology, and instructing the individual to develop operational competence. Ball, Beukelman, and Pattee evaluated the speech performance of 158 different people with ALS at three-month intervals from diagnosis to death and reported this in 2002. Current data from the same database will be presented for a minimum of 300 people with ALS, reflecting AAC use patterns through June of 2008. New data indicate that AAC finders should be aware that on average, persons with bulbar ALS use AAC technology for 25 months and those with spinal ALS for 31 months (Ball, Beukelman, Robertson, & Pattee (In press).

AAC Finders communicate with those with ALS and their decision-makers about initiating an AAC assessment to allow them sufficient time to become proficient communicators with the new technology. The Finder also prepares them to make a decision to move forward with AAC assessment while their natural speech is still quite understandable. This is rather unique decision-making strategy is specific to ALS; usually people seek medical or allied health interventions when their symptoms are obvious and resulting in significant impairments. AAC Finders help to make it evident to the person with ALS that he/she will have success at communication using AAC technology.

AAC Specialists and ALS

AAC Specialists become particularly active in another phase, the Assess, Recommend and Implement AAC strategy phase. Assisted by the general practice clinician; the AAC Specialist works with the person with ALS and his or her key decision-makers to identify communication interaction and participation needs. As with determining participation needs, data are presented from the NE database that support the idea that AAC assessment and recommendations should also consider decisions that the individual is making about medical care and support; including decisions such as artificial ventilation, that will extend the duration of life. Data from the NE database support that these decisions will increase the length of time that they will use AAC technology, while surviving with minimal movement capability (Ball, et al., 2007).

AAC specialists collaborate with General practice clinicians and the person with ALS' support staff in a third phase; this phase involves activities of adapting and accommodating the AAC options to the changing lifestyle and needs of the individual. Data from the NE database indicate specific activities such as optimizing AAC use in preferred locations (e.g., wheelchair, lift chair/recliner, kitchen, office, bed). This collaboration is also vital in developing low-tech communication supports to meet communication needs not met with technology.

General Practice Clinicians and ALS

General practice clinicians often collaborate with an AAC specialist during assessment, recommendation and prescription-obtaining activities. Importantly, they also typically play a key role in instruction of the person with ALS who relies on AAC, their AAC facilitators, and some of their communication partners. In addition, they are active in adapting AAC options to meet the individuals' changing physical and communication needs. In particular, they play an important role in supporting the development of multi-modality communication options that include low-technology as well as high technology options.

AAC Facilitators and ALS

Ball, Schardt, Beukelman, and Pattee (2005, November) reported that of 47 individuals with ALS, all (100%) had AAC facilitators who supported them. Usually (96%), these individuals were family members, friends, or caregivers. Few (4%) professional clinicians filled this role. Facilitators typically ensured that the AAC technology was maintained, electrically charged and properly programmed. In addition, they instructed communication partners and listeners who experienced difficulty with the technology and/or communication. When problems occurred, the facilitator usually contacted the manufacturer or commercial company that vended the AAC device, the general practice clinician, or the AAC specialist for assistance. Facilitators in the Ball et al study (2005) reported that they received on average 2.5 hours of instruction in the operation of the AAC device; and likewise reported that amount of instruction to be adequate for their needs. In addition, many facilitators observed the instruction that the individual with ALS received from the AAC specialist, general clinician, or representative of the manufacturer. At that time, none of the facilitators reported receiving just-in-time instruction from the device itself or from internet resources. New data for an additional group of participants will be presented, reflecting nearly 100 persons with ALS which reflects up to date intervention strategies.

Individuals who communicate frequently with persons with ALS typically learn unique communication strategies not utilized by most listeners. These include implementing a range of different high and low-tech communication options. These communication partners are usually instructed by the individual with ALS who has CCN, the General practice clinician, or the AAC Facilitator. Some strategies these people provide include: (1) establishing reliable nonverbal signals; (2) knowing how and when to provide appropriate options to resolve communication breakdowns; and (3) sharing a communication duet to assist other people who are unfamiliar the individual's communication strategies. To date, the authors are unaware of a communication partner who received just-in-time instruction from other sources.

AAC Experts and ALS

Experts fill a number of different roles with regard to AAC for persons with ALS. They do research, prepare instructional materials such as webcasts, textbooks, and clinical books, and develop new technology. Some of them instruct AAC specialists and General practice clinicians. Many teach at universities where they provide pre-professional preparation in AAC as it relates to a variety of populations and/or in ALS as it compromises speech function neurologically. They help shape and implement public policy. At times, they fill a dual role of AAC specialist and AAC expert.

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